A Training Curriculum

for paraprofessionals who are functioning
as caretakers of American's chronic
HIV / AIDS infected individuals

The Final Demand: Case Managing AIDS

developed by

Jackson State University
National Alumni AIDS Prevention Project*

Veronica Hartwell and Peter Gaddis, Jr., Authors

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A Training Curriculum

The Final Demand: Case Managing AIDS

In this Curriculum

INTRODUCTION

As this is the second decade of the HIV disease, as we know it, the rising number of AIDS cases and the availability of healthcare and healthcare professionals are becoming a critical concern in many programs. The forecast for future AIDS cases versus healthcare services and case manager availability, is very dismal according to some research indications. Research suggests that a large number of individuals:

1) Understand how HIV is, and is not transmitted and how to prevent its transmission;

2) Have been inundated with information about HIV thereby desensitizing them to it as a health concern; and

3) Understand that anyone can contract HIV from practicing unsafe behaviors, but continue to believe that HIV only affects specific groups of people.

Consequently, as long as the mind set of individuals continues to reflect the prestated view, and because a vaccine or cure may not be discovered soon, the number of AIDS cases and the need for continued care for people living with AIDS will constantly rise. We can also anticipate that, as the number of cases and the need for healthcare services increase, the quality of services provided may decline. More trained service providers and resource individuals will be needed.

FOREWORD

"The Final Demand: Case Managing AIDS" is a training curriculum which resulted from a research study that investigated 560 HIV/AIDS service providers and case managers' knowledge about AIDS; their attitudes toward working with people living with AIDS (PLWA); and their beliefs about self-competency and areas requiring additional training.

It is believed that professional care partners and case managers, who are working with PLWAs, must be properly trained to meet some of the unique demands of a PLWA to assure, to the maximum extent possible, that the PLWA has assess to and receives all resources and services which may assist them in reaching their optimal level of functioning.

ACKNOWLEDGMENTS

Acknowledging the many people who contributed to the development of this curriculum requires us to express our appreciation to HIV/AIDS service providers and case managers who completed the assessment and colleagues and staff of the National Alumni AIDS Prevention Project.

Special thanks are extended to the project's material Review Panel for their critical and substantial feedback on the content of the curriculum.

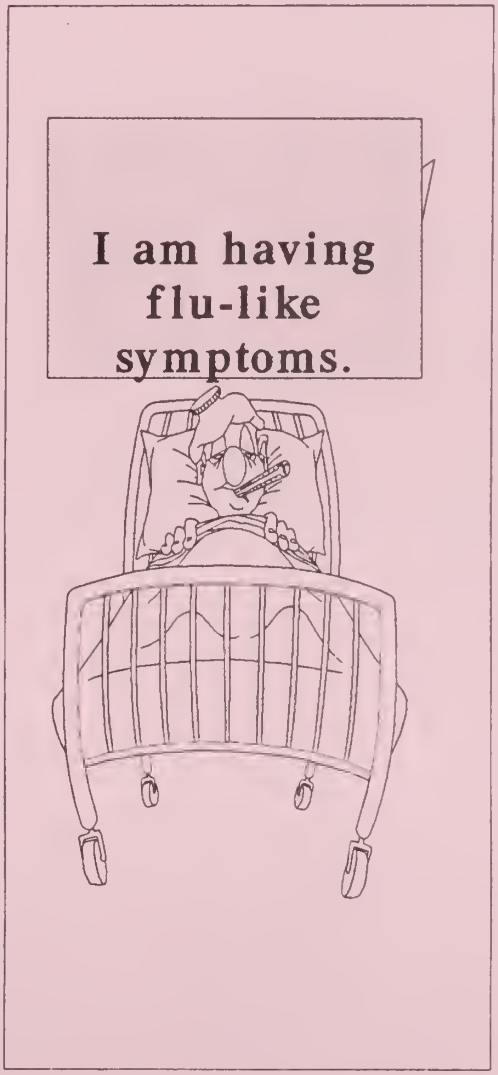
National Alumni AIDS Prevention Project

INSTRUCTIONS FOR THE USER

This publication is a curriculum. It is not intended to be a blueprint for a successful service provider program. It does not address in-depth such issues as insurance, medication, or current laws. It is designed to develop beginning skills in case management and to assist those individuals who suddenly find themselves caring for a chronically ill person who is living with AIDS. Current PLWA needs and different service provider environments affect how a training tool is used. This curriculum contains specific information on areas needed most in working more effectively with PLWAs living in a hospice setting or in their own home environment.

Chapter 1

What About AIDS?



In This Chapter

- What is AIDS?
- What causes AIDS?
- Spectrum of AIDS
- Routes of Transmission
- Symptoms of AIDS
- Ways HIV cannot be Spread
- HIV antibody Testing
- Ways to prevent contracting HIV
- Behaviors at risk of HIV
- Just for Review

CHAPTER 1
WHAT ABOUT AIDS?

AIDS is an acronym for Acquire Immune Deficiency Syndrome. **AIDS** is a disease that makes the body too weak to fight off infections. People with **AIDS** get sick and often die because there is no cure.

Each of the letters in AIDS stands for a word.

A CQUIRED

Acquired means the disease is passed from one person to another through blood-to-blood and sexual contact. It is not hereditary.

I MMUNE

Immune means the body's defense system, which normally protect us from disease.

D EFICIENCY

Deficiency means the defense system is not working.

S YNDROME

Syndrome is a group of symptoms which, when they occur together, means a person has a particular disease or condition.

CHAPTER 1
WHAT ABOUT AIDS?

WHAT CAUSES AIDS?

AIDS is caused by a virus called the Human Immunodeficiency Virus (HIV). The virus breaks down the body's immune system, leaving the person defenseless against life threatening illnesses. The virus then causes various symptoms within the body and the result is AIDS.

CHAPTER 1
WHAT ABOUT AIDS?

THE SPECTRUM OF HIV

HIV infection is the first stage of AIDS. Most HIV infected individuals have no symptoms at all. They look, act, and feel well.

The final stage on the HIV spectrum is AIDS, which is evidenced after an HIV infected individual has experienced opportunistic infections.

Opportunistic infections are a variety of diseases which occur in individuals who do not have healthy immune systems. Opportunistic infections seen in AIDS patients include pneumocystis carinii pneumonia, disseminated herpes infections, atypical mycobacteria, toxoplasmosis and cryptosporidiosis.

ROUTES OF TRANSMISSION

The **H**uman **I**mmunodeficiency **V**irus (**HIV**) can be transmitted by direct contact with infected body fluids including:

- semen,
- vaginal fluids,
- blood products, and
- breast milk

CHAPTER 1
WHAT ABOUT AIDS?

SYMPTOMS OF AIDS

The following are some common symptoms of a person with AIDS.

- Extreme tiredness, sometimes combined with headaches, dizziness or lightheadness;
- Swollen lymph glands in the neck, armpits or groin;
- Continued fever;
- Continued night sweats;
- Weight loss of more than 10 pounds which is not due to dieting or increased physical activity;
- Purple or discolored growths on the skin or the mucous membrane (inside the mouth, anus or nasal passages);
- Heavy, continued dry cough that is not from smoking or that has lasted too long to be a cold or flu;
- Continuing bouts of diarrhea;
- Thrush, a thick whitish coating on the tongue or in the throat which may be accompanied by sore throat;
- Unexplained bleeding from any body opening or from growths on the skin or mucous membranes; bruising more easily than usual;

SYMPTOMS OF AIDS CONTINUED

- Progressive shortness of breath; and
- Forgetfulness, confusion, disorientation and other signs of mental deterioration.

People with AIDS may suffer from a variety of opportunistic infections. (Most of their illnesses would not readily invade someone with a healthy immune system.) In addition, people with AIDS may have trouble with the function of certain body organs: lungs, liver, kidneys, intestines, and heart. Each infected person may have a different set of signs and symptoms.

You should remember two things:

1. All HIV-infected people can infect others with the virus even if they look and feel healthy.
2. Having these signs or symptoms may indicate symptomatic HIV infection.

Only a doctor can tell you what the symptoms mean.

WAYS HIV CANNOT BE SPREAD

There is no evidence that HIV can be spread through any kind of casual contact.

Research reports that AIDS cannot be spread by:

- Sitting next to someone infected with HIV
- Hugging someone infected with HIV
- Holding or shaking hands of someone with HIV
- Sharing eating utensils or glasses of someone infected with HIV
- Using recreational or toilet facilities after someone infected with HIV
- Swimming in the same pool with someone infected with HIV
- Accepting served food from somone infected with HIV
- Sleeping in the same room with someone infected with HIV
- Having an HIV infected person sneeze, cough, or spit on someone
- Mosquitoes
- Kissing

HIV ANTIBODY TESTING

At the present time, there are tests designed to detect HIV, the virus that causes AIDS. The blood tests that are used (**Elisa and Western Blot**), detect the antibodies that have been developed by the body's immune system to fight off the invasion of HIV. The significance of this fact is that the virus can be present in a person's body for some time before antibodies develop. This period usually lasts between 6 to 12 weeks. However, it can take up to 6 months after infection for the antibody tests to show positive results.

The **Elisa is an acronym for "enzyme-linked immuno sorbent assay,"** a test used to detect antibodies against HIV in blood samples. The **Elisa** is the most commonly used test designed to detect the presence of HIV antibodies.

The **Western Blot** is an antibody test for HIV. It is more difficult, more expensive, and time consuming. The **Western Blot** is a more specific test that is used to confirm the results of the **Elisa**.

SUGGESTED WAYS TO PREVENT CONTRACTING HIV

The following are suggested behavioral practices to prevent contracting HIV.

- **Abstinence**--Abstinence means not having any sexual contact with a man or woman.
- **Mutually committed monogamous relationship (MCM)**--MCM means having sex with your wife, husband or significant other and no one else.
- **Practice safer sex (PSS)**--PSS means that if a person decides to have sex outside MCM, or casually, he/she should use condoms and spermicides during sexual activity. Talk to your sex partner about health, previous sexual relationships and safer sex.
- **Don't mix alcohol and other drugs with sex**. When mixing of alcohol and illicit drugs, e.g., herion, cocaine, and PCP with sexual activity, the drugs may impair a person's judgment.
- **Avoid unprotected sex**. Studies indicate that the risk for HIV infection increases with the number of sex partners. Practice safer sex.

CHAPTER 1
WHAT ABOUT AIDS?

Don't share needles (DSN)--DSN means that a person should not share needles when using any drugs e.g., steroids, herion, cocaine or when tattooing or ear piercing.

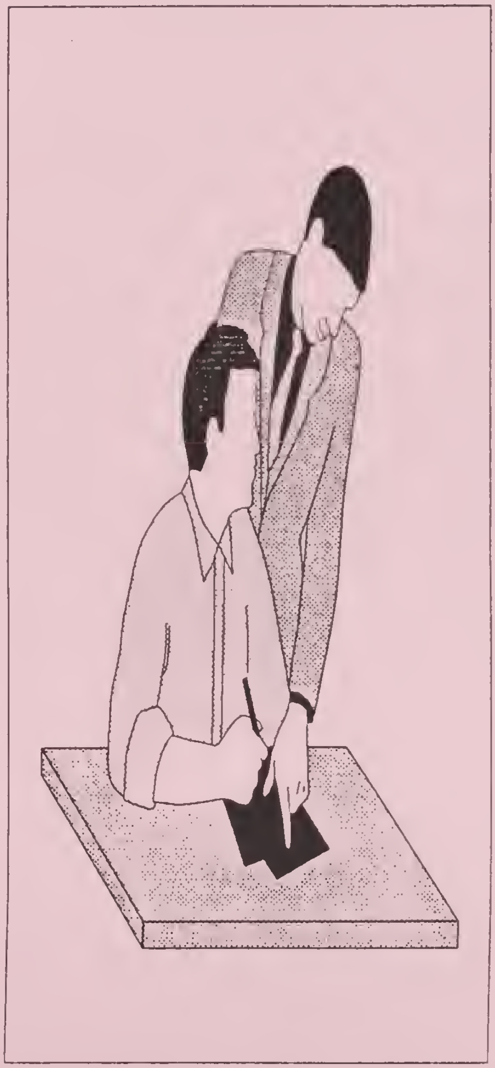
JUST FOR REVIEW

Do you know the answers to the following questions? You **DO NOT** have to write down the answers. But, if in doubt, go back and review the sections that gave you trouble.

1. What do the letters in AIDS stand for?
2. What is the name of the virus that causes AIDS?
3. What are opportunistic infections?
4. Explain the spectrum of HIV.
5. What are the routes of HIV transmission?
6. List the symptoms related to AIDS.
7. Can a person become infected with HIV through casual contact?
8. What is the difference between the ELISA and WESTERN BLOT?
9. How can you protect yourself from contracting HIV?
10. What type of behaviors put a person at risk of contracting HIV?

Chapter 2

Your Role as a Case Manager



In This Chapter

- What is Case Management?
- What is a Case Management Program?
- Your Role as a Case Manager
  - a. Do's
  - b. Don't's
- Just for Review

CHAPTER 2
YOUR ROLE AS A CASE MANAGER

WHAT IS CASE MANAGEMENT?

Case management is considered a valuable service. Coordinated efforts on the part of all who are involved in the provision of services to the person with HIV as well as family members and significant others, are essential if effective, appropriate services are to be provided in an efficient manner. However, as a first time case manager or caregiver, to be effective, you should coordinate with as many agencies as possible so you can make the necessary referrals when they arise.

CHAPTER 2
YOUR ROLE AS A CASE MANAGER

WHAT IS A CASE MANAGEMENT PROGRAM?

A case management program requires a coordinated effort at the local level to take responsibility for a person living with AIDS (PLWA) and establish a comprehensive service or care program.

An ideal program will:

a. Assign every PLWA a single case manager.

b. Assure that PLWAs are seen at least once a month.

c. Have a comprehensive file on community resources which includes:
    1. name of agency
    2. contact person
    3. services available
    4. eligibility requirements
    5. telephone numbers

d. Assess the PLWA's needs for services and develop a written treatment plan that provides a range of services that should include:

1. services to be rendered by the case manager,
2. frequent visits,
3. treatment objectives,
4. referral,
5. advocacy,
6. monitoring, and
7. follow-up

The case manager should work collectively with all agencies to assure that the PLWA receives maximum care.

CHAPTER 2
YOUR ROLE AS A CASE MANAGER

WHAT IS THE ROLE OF THE CASE MANAGER?

The case manager working with PLWAs will be faced with many problems and concerns. To function efficiently, the case manager should be knowledgable about the following:

1. **Outreach Services**--meals on wheels, pastoral counseling and other outreach programs.

2. **Intake Services**--Case managers should obtain complete profile data on all PLWAs including medications used, contact with other agencies, addresses, phone numbers, family background, and other relevant information.

3. **Emergency/Crisis Intervention**--Case managers should be aware of resources and procedures for emergency placement or intervention when a PLWA is in need of immediate attention such as respite services at state residential facilities, hospital admission, and other services.

4. **Information and Referral**--Case managers will provide PLWAs, families and other service agencies with information regarding placement sites, financial resources, application procedures, and other information.

5. The case manager should have knowledge of or be able to obtain information about programs and services he/she will be responsible for referring a PLWA.

6. **Needs Assessment**--After a PLWA has had a comprehensive evaluation and the case manager has met with the PLWA and family, the case manager should be able to identify all areas of need, and complete a treatment or service plan for the PLWA.

7. **Service Planning**--The case manager must develop a service plan for the PLWA based on the needs assessment. This plan would address immediate and long-range service needs and would be subject to change as the PLWAs needs change.

8. **Service Coordination**--The case manager will assess the availability of all services needed by the PLWA and make appropriate referrals.

9. **Monitor**--The case manager will stay in contact with the PLWA and service agencies once a PLWA has been referred for services. This is to ensure that the PLWA receives the services requested.

An additional responsibility of the case manager is to ensure that the housing environment of the person with HIV infection is adequate.

1. The individual must have their own bed when medical care requires it.
2. There must be adequate heating.
3. There must be adequate bathing and toilet facilities.
4. There must be electricity.
5. There must be a telephone or access to a telephone.
6. Cooking facilities must be available.
7. Fire and safety standards must be met.

That is not to say that services cannot be provided in situations which do include all the above. However, if they are not present, the level and quality of services may be limited.

A FEW DO'S AND DON'T'S OF CASE MANAGING

DO:

Keep It Simple

As an individual just beginning to work with the terminally ill or seeing their first PLWA, you may find your own anxiety levels high. This inner discomfort can lead to excessive talking; the use of confusing language; stiff body posture; or failure to give the PLWA adequate opportunity to talk or ask questions. If you are experiencing any of these symptoms, just take it slow and keep the conversation short and simple.

Wait for Questions

Create an atmosphere where the PLWA is comfortable and able to communicate by:

1. Expressing feelings without disruption,
2. Knowing that you are willing to listen, and
3. Asking relevant questions.

CHAPTER 2
YOUR ROLE AS A CASE MANAGER

Find Out What The Diagnosis Means to the PLWA:

The PLWA's interpretation of and personal meanings attached to their condition can be helpful in understanding how it is affecting them.

Check For Understanding:

After you have provided information to the PLWA, see what has been understood. Allow the PLWA time to repeat and discuss the information that you have shared.

DON'T:

Don't Feel That You Have To Provide Answers to Every Question That Arises:

People can absorb, recall, and mull only a limited amount of information at one time. There is no reason to feel that all the information requested should be provided at once.

i.e. Be empathic--"I know that you have a lot of questions and concerns, but we do not have to answer everything now--today."

Don't Argue With Denial:

If the PLWA wants or needs to deny after a certain point, respect his or her right to do so. Allow for denial and don't become overly confrontive. As the person's trust and confidence increases, communication may open.

JUST FOR REVIEW

Do you know the answers to the following questions? You **DO NOT** have to write down the answers. But, if in doubt, go back and review the sections that gave you trouble.

1. What is case management?

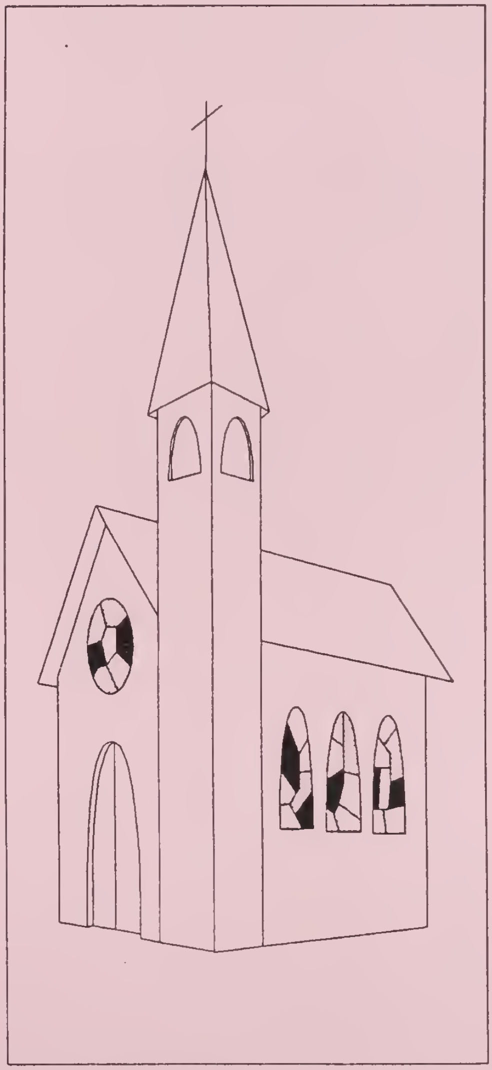
2. What services are required in a case management program?

3. What is the role of the case manager?

4. What are some of the do's and don't's of case managing?

Chapter 3

Death and Dying



In This Chapter

- ˜ How Death is Denied
- ˜ The experience of Dying
- ˜ Making life easier for the Dying
- ˜ Practicalities of Death
- ˜ Taking control of your own Death "a Questionnaire"
- ˜ Just for Review

CHAPTER 3
DEATH AND DYING

HOW IS DEATH DENIED

Death is the natural completion of things and as much a part of the real world as life itself. A case manager will be faced with PLWAs dying almost on a daily basis. It is important that the case manager is able to deal with another person's death as well as their own mortality.

Most PLWAs prefer to know the truth about their health and chances for recovery. Even when they are not officially informed by a doctor or relative, most fatally ill people know or strongly suspect they are dying.

CHAPTER 3
DEATH AND DYING

THE EXPERIENCE OF DYING

An individual who is approaching death usually makes it clear whether he or she wants to talk about death and to what extent. The most frequent concern is how much time is left. The case manager should be aware that the PLWA may or may not experience the following emotional stages:

- **Denial ("No, not me.")**
- **Anger ("Why me?")**
- **Bargaining ("Yes, me, but...")**
- **Depression ("Yes, it's me.")**
- **Acceptance ("Yes, me; and I'm ready.")**

CHAPTER 3
DEATH AND DYING

DENIAL ("NO, NOT ME.")

When informed of impending death, a terminally ill person or PLWA may reject the news. The denial overcomes the initial shock, and allows the person to begin to gather his or her defenses. Denial, at this point, is a healthy defense mechanism. It can become counter productive/unhealthy, however, if it is reinforced and encouraged by the relatives and friends of the dying PLWA.

ANGER ("WHY ME?")

In the second stage, a PLWA may begin to feel resentment and rage toward his or her impending death. The anger may be directed at the PLWAs family or medical staff; but there is very little that can be done except try to endure such encounters, comfort the PLWA, and help him or her on to the next stage.

BARGAINING ("YES, ME, BUT...")

In this stage, a PLWA may try to bargain, usually with his or her God, for a way to reverse, or at least postpone dying. The PLWA may promise, in exchange for recovery, to become devoted to good works or to see his or her family more. Alternatively, he or she may say "Let me live long enough to see my grandchild born," or "...to see the spring again."

DEPRESSION ("YES, IT'S ME.")

In the fourth stage, the PLWA may gradually realize the full consequences of his or her condition. This may begin as grieving for health that has been lost, and then become anticipatory grieving for the loss that is to come of friends, loved ones, and life itself. This is perhaps the most difficult time, and the dying person should not be left alone. Neither should one try to cheer up the PLWA, for he or she must be allowed to grieve.

ACCEPTANCE ("YES, ME; AND I'M READY.")

In this last stage, the PLWA has accepted the reality of his/her death: The moment looms as neither frightening nor painful, neither sad nor happy--only inevitable. As he or she awaits for the end of life, he or she may ask to see fewer visitors, to separate from other people, and perhaps to turn to one person for support.

YOU CAN HELP A DYING PERSON

As a case manager, you may be reluctant to visit, either because of your discomfort or because you feel you cannot help much (especially if the PLWA is not conscious or lucid). However, your presence can fill a crucial human need for the PLWA; it can convey the message that he or she is not left all alone.

1. Don't worry about what to say. Your words matter less than your presence. Just being there, holding hands, can be a comfort.
2. Listen. Dying people often need someone to listen as they talk through their feelings. Such discussions don't make them more upset but help them come to terms with what is happening.
3. Be genuine. Don't try to look or act cheerful. The PLWA will see through you and feel more isolated than before. It's better to let your sadness and concerns show.
4. Don't try to explain or rationalize what has happened.

CHAPTER 3
DEATH AND DYING

YOU CAN HELP A DYING PERSON

Knowing What Not To Say. Sometimes poorly chosen words, meant to comfort, only make a grieving person feel worse. As a case manager or care giver, here are some words to avoid:

1. "It's God's will."
2. "You're so strong. It's fortunate this happened to someone like you who can handle it."
3. "I understand."
4. "It was a blessing."
5. "You should sell this house right away. It's too big for you now."

Such statements maximize the person's anguish, make them feel guilty about the way they feel, or may seem insensitive.

YOU CAN HELP A DYING PERSON

Suggested Ways to Comfort Grieving Friends of the PLWA

1. Be there. Your presence will let his/her friends know you care. A hug can communicate more than a thousand words.

2. Listen. Bereaved individuals need to talk out their feelings--often again and again.

3. Write a simple note. A few phrases, such as "I want to let you know I'm thinking of you and praying for you," mean a great deal. A small gift, such as a book or a plant, is also thoughtful.

4. Ask what you can do?

CHAPTER 3
DEATH AND DYING

KNOW THE PRACTICALITIES OF DEATH

A growing movement throughout the United States has been that of memorial societies, voluntary groups that help people plan in advance for death. These societies have the advantage of obtaining services at moderate cost; keeping the arrangements simple and dignified; and--most important, perhaps--easing the emotional and financial burden on the rest of the family when death finally does come.

Suggested Ways to Handle Funeral Arrangements

1. Contact several undertakers or funeral directors before death or as soon as possible after the physician has signed the death certificate.

2. Even though you may not feel like it, try to obtain cost estimates from more than one undertaker.

3. Have someone--a lawyer, clergyman, or friend--who was not as personally involved with the dead person accompany you to the funeral home to make the arrangements if the family request your assistance. This person can be more objective in making arrangements that suit the family's financial resources.

4. Most funeral homes charge a fee that includes the coffin, preparation of the body for burial, and routine procedures such as filing the death certificate and putting appropriate notices in the newspapers. Find out exactly what is and is not included in the fee, what is extra, and what the family will have to take care of. Also, be aware that some funeral homes charge extra or are reluctant to handle HIV infected individuals.

KNOW THE PRACTICALITIES OF DEATH

5. Find out if the deceased's insurance policies, trade or credit unions, or fraternal organizations have death benefits that will help pay funeral expenses. Social Security may also provide some death benefits.

CHAPTER 3
DEATH AND DYING

ASSESS YOUR OWN FEELINGS ABOUT DEATH
TAKE THIS DEATH QUESTIONNAIRE

Purpose

This questionnaire is not designed to test your knowledge as a case manager. Instead, it should encourage you to think about your present attitudes toward death and how these attitudes may have developed. The questionnaire is also designed to assess your feelings, and whether you will be able to work effectively with someone who is dying.

Directions

Answer the questions to the best of your knowledge, by circling the appropriate letter.

1. Who died in your first personal involvement with death?

   a. grandparent or great-grandparent
   b. parent
   c. brother or sister
   d. friend or acquaintance
   e. stranger
   f. public figure
   g. animal

2. To the best of your memory, at what age were you first aware of death?

   a. under 3 years
   b. 3 to 5 years
   c. 5 to 10 years
   d. 10 years or older

QUESTIONNAIRE CONTINUES

3. When you were a child, how was death talked about in your family?

   a. openly
   b. with some sense of discomfort
   c. only when necessary and then with an attempt to exclude children
   d. as if it was a taboo subject
   e. do not call any discussion

4. Which of the following best describes your childhood conceptions of death?

   a. Heaven-and-Hell concept
   b. afterlife
   c. death as sleep
   d. cessation of all physical and mental activity
   e. mysterious and unknowable
   f. something other than the above
   g. no conception
   h. can't remember

5. To what extent do you believe in a life after death?

   a. strongly believe in it
   b. tend to believe it
   c. uncertain
   d. tend to doubt it
   e. convinced it does not exist

CHAPTER 3
DEATH AND DYING

QUESTIONNAIRE CONTINUES

6. Regardless of your beliefs about life after death, what are your feelings about it?

   a. I strongly wish there were a life after death.
   b. I am indifferent as to life after death.
   c. I definitely prefer that there not be a life after death.

7. Has there been a time in your life when you wanted to die?

   a. yes, mainly because of great physical pain
   b. yes, mainly because of great emotional upset
   c. yes, mainly to escape an intolerable social or interpersonal situation
   d. yes, mainly because of great embarrassment
   e. yes, for a reason other than above
   f. no

8. What does death mean to you?

   a. the end, the final process of life
   b. the beginning of a life after death, a transition, a new beginning
   c. a joining of the spirit with a universal cosmic consciousness
   d. a kind of endless sleep, rest and peace
   e. termination of this life but survival of the spirit
   f. don't know
   g. other (specify)____________________

QUESTIONNAIRE CONTINUES

9. What aspect of your own death is the most distasteful to you?

   a. I could no longer have any experiences.
   b. I am afraid of what might happen to my body after death.
   c. I am uncertain as to what might happen to me if there is a life after death.
   d. I could no longer provide for my dependents.
   e. It would cause grief to my relatives and friends.
   f. All my plans and projects would come to an end.
   g. The process of dying might be painful.
   h. Other (Specify)____________________

10. How do you rate your present physical health?

    a. excellent
    b. very good
    c. moderately good
    d. moderately poor
    e. extremely bad

11. How do you rate your present mental health?

    a. excellent
    b. very good
    c. moderately good
    d. moderately poor
    e. extremely poor

QUESTIONNAIRE CONTINUES

12. Based on your present feelings, what is the probability of your taking your own life in the near future?

a. extremely high (feel very much like killing myself)
b. moderately high
c. between high and low
d. moderately low
e. extremely low (very improbable that I would kill myself)

13. In your opinion, at what age are people most afraid of death?

a. up to 12 years
b. 13 to 19 years
c. 20 to 29 years
d. 30 to 39 years
e. 40 to 49 years
f. 50 to 59 years
g. 60 to 69 years
h. 70 years and over

14. When you think of your own death (or when circumstances make you realize your own mortality), how do you feel)

a. fearful
b. discouraged
c. depressed
d. purposeless
e. resolved, in relation to life
f. pleasure, in being alive
g. other (specify)_________________

QUESTIONNAIRE CONTINUES

15. What is your present orientation to your own death?

a. death-seeker
b. death-hastener
c. death-accepter
d. death-welcomer
e. death-postponer
f. death-fearer

16. If you were told that you had a terminal disease and a limited time to live, how would you want to spend your time until you died?

a. I would make a marked change in my life-style to satisfy hedomistic needs (travel, sex, drugs, or other experiences).
b. I would become more withdrawn--reading, contemplating, or praying.
c. I would shift from my own needs to a concern for others (family or friends).
d. I would attempt to complete projects, to the up loose ends.
e. I would make little or no change in my life-style.
f. I would try to do one very important thing.
g. I might consider committing suicide.
h. I would do none of these.

17. How do you feel about having an autopsy done on your body?

a. approve
b. don't care one way or the other
c. disapprove
d. strongly disapprove

Now examine your attitudes towards death and discuss your feelings with co-workers, friends, and family. Although we read about death in the newspapers every day, we rarely come in close contact with it. Our society tends to reinforce the denial of death. By completing this questionnaire, you are taking a step toward facing the reality of death, and may now be able to work more effectively with persons who are dying.

CHAPTER 3
DEATH AND DYING

JUST FOR REVIEW

Do you know the answers to the following questions? You **DO NOT** have to write down the answers. But, if in doubt, go back and review the sections that gave you trouble.

1. Describe the spectrum of emotions that may be experienced by a dying person?
2. What are the emotions experienced by those close to the dying person?
3. What are some of the strategies of helping a dying person?

Chapter 4

Dealing with Burnout

In This Chapter

- Defining Burnout
- Recognizing Burnout
- Components of Burnout
- Strategies for Dealing with Burnout
- Are you burning Out? "an Assessment"
- Just for Review

CHAPTER 4
DEALING WITH BURNOUT

WHAT IS BURNOUT?

> **BURNOUT:** *To deplete oneself. To exhaust one's physical and mental resources. To wear oneself out by excessively striving to reach some unrealistic expectation imposed by oneself or by the values of society.*

Burnout is informally defined as a state of mind that frequently affects individuals who work with other people (especially but not exclusively in the helping professions) and who pour in much more than they get back from the people they work with, supervisors, and colleagues.

Being burned out is "a state of fatigue or frustration brought about by devotion to a cause, way of life, or relationship that failed to produce the expected reward."

Burnout is a chronic condition, something a person has been working toward over a period of weeks, months, even years.

CAHPTER 4
DEALING WITH BURNOUT

RECOGNIZING BURNOUT

A case manager will frequently experience burnout. It is important that they recognize the signs.

SIGNS OF BURNOUT:

Some of the major symptoms associated with burnout include:

- General malaise
- Emotional, physical and psychological fatigue
- Feelings of helplessness/hopelessness
- Lack of enthusiasm about work/life in general
- Irratibility
- Loss of patience
- Preoccupation--daydreaming or spacing out
- Lack of interest
- Accident prone
- Emotional outburst and crying
- Withdrawal
- Depression
- Hostile and assaultive behavior
- Tendency to blame others
- Increased smiling
- Reduced creativity

CHAPTER 4
DEALING WITH BURNOUT

SOME COMPONENTS OF BURNOUT

Physical Exhaustion

One of the components of burnout is physical exhaustion. Physical exhaustion is characterized by low energy, chronic fatigue, weakness, and weariness. People who have burned out report such things as accident-proneness, increased susceptibility to illness, frequent headaches, nausea, muscle tension in shoulders and neck, back pains, and changes in eating habits and weight. Some individuals experience psychosomatic complaints such as increased frequency of illness, nagging colds, and frequent attacks of virus of flu.

Emotional Exhaustion

Another component of burnout is emotional exhaustion. Emotional exhaustion involves feelings of depression, helplessness, hopelessness, and entrapment leading to extreme cases to mental illness or thoughts about suicide. It may cause incessant, uncontrollable crying or the loss of coping and control mechanisms. People who burnout feel that they need all of the little emotional energy they have left to keep going through the motions of life. Some case managers may feel that they have nothing left to give to anyone.

Mental Exhaustion

Mental exhaustion is characterized by the development of negative attitudes toward one's self, work, and life. People who are bored often report dissatisfaction with their work and way of life and a lowered self-concept. They feel inadequate, inferior, and incompetent. They may feel incompetent in dealing with the requirements of their job. In addition, they may feel worthless, like a total failure and resent anyone who witnesses their failure.

CHAPTER 4
DEALING WITH BURNOUT

HERE ARE SOME STRATEGIES FOR DEALING WITH BURNOUT

The major strategies for dealing with burnout consist of:

- being aware of the problem;
- taking responsibility for doing something about it;
- achieving some degree of cognitive clarity; and
- developing new ways for coping, improving the range and quality of old ways.

Awareness

Awareness is the first step in effectively dealing with burnout. Become fully aware of the problem and the cause. Be aware, however, that with awareness comes a temporary increase in the pain until the action is taken. Awareness is the simple realization that there is a problem; the other part is the awareness that the problem is largely caused by the situation rather than by one's own emotional inadequacy.

HERE ARE SOME STRATEGIES FOR DEALING WITH BURNOUT

Take Responsibility for Action

Assume more power and control over your life through the realization that there are more things that you can do to gain control over the environment than you realize. Reduce the debilitating effects of feeling helpless by taking responsibility for effecting changes in difficult situations.

Obtain Cognitive Clarity

"Cognitive clarity" is the development of an ability to distinguish between those aspects that can't be changed and those that can. This allows you to channel your efforts where there will be a great likelihood of important progress.

Develop Tools for Coping

Practice looking inward. Learn to articulate clearly what your own needs are in a given situation. If a solution involves meeting with other people to discuss problems and solutions, certain skills such as "active listening" and clear communication need to be developed.

CHAPTER 4
DEALING WITH BURNOUT

CHECK YOURSELF
ARE YOU BURNING OUT?

Look back over the past six months. Have you been noticing changes in yourself or in the world around you? Think of the office...the family...social situations. Allow about 30 seconds for each answer. Then assign it a number from 1 (for no or little change) to 5 (for a great deal of change) to designate the degree of change you perceive. (1 2 3 4 5)

1. Do you tire more easily? Feel fatigued rather than energetic?_____
2. Are people annoying you by telling you, "You don't look so good lately"?_____
3. Are you working harder and harder and accomplishing less and less?_____
4. Are you increasingly cynical and disenchanted?_____
5. Are you often invaded by a sadness you can't explain?_____
6. Are you forgetting? (appointments, deadlines, personal posessions)_____
7. Are you increasingly irritable? More short-tempered? More disappointed in the people around you?_____
8. Are you seeing close friends and family members less frequently?_____
9. Are you too busy to do even routine things like make phone calls or read reports or send out your Christmas cards?_____

BURNOUT ASSESSMENT CONTINUES

1 2 3 4 5

10. Are you suffering from physical complaints? (aches, pains, headaches, a lingering cold)_____

11. Do you feel disoriented when the activity of the day comes to a halt?_____

12. Is joy elusive?_____

13. Are you unable to laugh at a joke about yourself?_____

14. Does sex seem like more trouble than it's worth?_____

15.. Do you have very little to say to people?_____

Now, turn to the next page and see your burnout rating.

CHECK YOURSELF
ARE YOU BURNING OUT?

Very roughly, now, place yourself on the Burnout scale. Keep in mind that this is merely an approximation of where you are and useful as a guide on your way to a more satisfying life. Don't let a high total alarm you, but pay attention to it. Burnout is reversible, no matter how far along it is. The higher number signifies that the sooner you start being kinder to your yourself, the better.

THE BURNOUT SCALE

0 - 25	You're doing fine.
26 - 35	There are things you should be watching.
36 - 50	You're a candidate.
51 - 65	You are burning out.
over 65	You're in a dangerous place, threatening to your physical and mental well-being. Take action to change.

JUST FOR REVIEW

Do you know the answers to the following questions: You DO NOT have to write down the answers. But, if in doubt, go back and review the sections that gave you trouble.

1. What is burnout?
2. What are the signs of burnout?
3. What are the components of burnout?
4. What are some strategies for dealing with burnout?

Chapter 5

What's Next?

In This Chapter

- What's Next?

CHAPTER 5

WHAT'S NEXT?

No one has all the answers. However, the information provided in this curriculum attempts to provide you with an outline that will help you began working more effectively with persons living with AIDS. This curriculum does not provide detail steps for working with PLWAs, but was designed to provide the unskilled case manager an opportunity to enhance his or her skills.

The rest is up to you; Case Managing AIDS: The Final Demand!

Chapter 6

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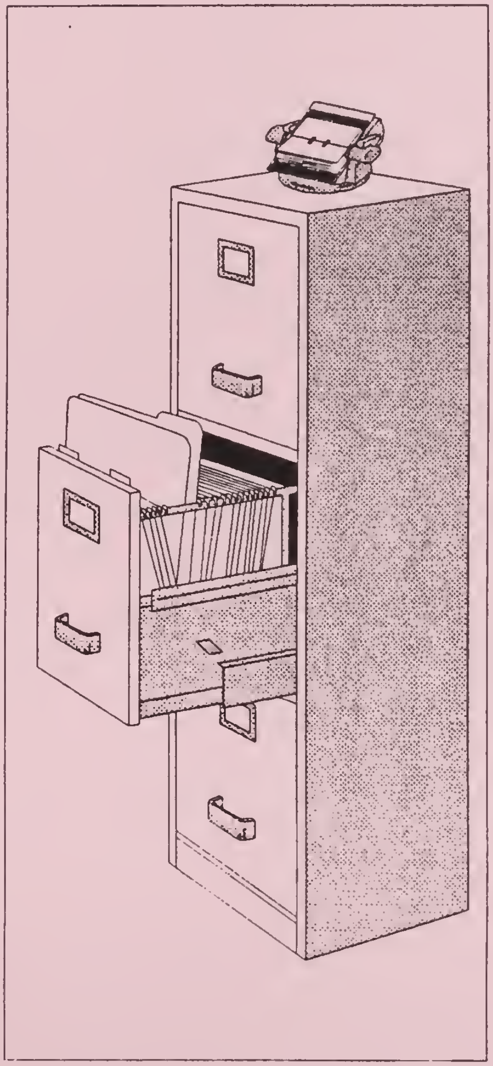

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